Kuru, AIDS and unfamiliar social behaviour - biocultural considerations in the current epidemic: discussion paper

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Cultural relativism in the study of infectious disease

As the magnitude and severity of the international AIDS epidemic persist and worsen, the concern of health professionals may soon reach a point of desperation. The impending spread of AIDS to previously unaffected regions in Asia, the Middle East and parts of South America, the increase in heterosexual transmission in Western Europe and North America, and the disturbing complex of neurological disorders associated with HIV infection that have been documented during the past year are factors which can only serve to heighten despondency in members of the medical community. In some, a sense of helplessness has perhaps given rise to futile speculation that, to paraphrase Kipling, by curtailing 'heathen folly' it would be possible to 'bid the sickness cease'.

Such an argument was advanced by Dr Seale (April 1987 *JRSM*, p 200) who attempted to equate kuru, a rare encephalopathy transmitted by ritual cannibalism, and AIDS as conditions unique to 'communities in which aberrant social behaviour had become elaborate cults within minority groups'[1]. If there are any similarities between kuru and AIDS, and this is not readily apparent, then the lesson to be learned from the response to kuru must surely be one of cultural sensitivity - not the sweeping condemnation of people whose mores might appear anomalous. Because unfamiliar behaviour has long been the domain of anthropologists their perspective and methods are particularly well suited to the study of practices which, in ethnocentric terms, 'most people . . . find abhorrent'[1] and from a medical point of view appear inimical to well being.

In analysing the social antecedents of health problems, perversion alone rarely accounts for the longevity of custom. Rather, longstanding practices almost invariably have some adaptive advantages that an untrained observer would be likely to overlook. Failure to grasp the functional role of seemingly unnatural acts may lead to the conclusion that their suppression is justified. It is rarely possible, however, to eradicate by fiat well entrenched behaviours; empirically, such tactics render poorly understood phenomena less accessible to study and eventual modification, though no less pervasive. Thus, the void in knowledge about disease transmission widens and medical researchers, who by virtue of their training generate hypotheses to explain incongruities, are hampered by inadequate data on which to base assumptions.

As the current AIDS epidemic escalates, clinicians cannot hope to diminish transmission by focusing solely on biomedical aspects of disease but must consider cultural factors in the spread of AIDS. The absence of an anthropological perspective precludes meaningful understanding of AIDS and gives rise to unfortunate social consequences - foremost of which is a tendency to blame victims of disease. It may be less readily apparent that disregard of the social dynamics involved in the spread of diseases such as kuru and AIDS also leads to critical scientific errors.

Reconsideration of kuru and AIDS underscores the importance of an anthropologically sound approach to the control of infectious disease. Given the exceptional virulence of AIDS and the lack of viable therapies and biological preventives, the only means at present of reducing person to person transmission is education, which is only effective if predicated upon in-depth understanding of prevailing knowledge, attitudes and practices related to HIV infection in diverse societies and subgroups. If superficially examined out of context, however, cross-cultural phenomena are easily distorted. Condemnation of unfamiliar practices serves no educational purpose for the public at risk, but may elicit 'justifiable' repulsion for those who, through their aberrant behaviour, would bring diseases such as AIDS and kuru upon themselves. To the extent that 'deviants' are already engaged in behaviour that 'most people . . . find shocking and repugnant'[1], also implicit in Seale's commentary is that they lack the degree of socialization to modify their behaviour; the most enlightened attempt at their reeducation would likely prove a waste of society's resources and it might be far more expedient to outlaw specific acts on 'religious, ethical and aesthetic grounds'[1].

Legal remedies

Such fiat power, however, has no basis in the legal tradition of secular societies. In the case of kuru, termination of the epidemic did not follow '. . . rigorous control, by the state, of a single form of deviant social behavior'[1]. While there may have been some degree of official opprobrium regarding the practice, cannibalism was never explicitly outlawed in New Guinea during the 1950s. The only references to corpses in the Queensland Criminal Code, which was enacted in 1899 and adopted by the Government of Papua in 1902, are as follows:

> [Sections governing] misconduct relating to corpses [provide that] . . . any person who, without lawful justification or excuse, the proof of which lies on him, improperly or indecently interferes with . . . any dead human body . . . is guilty of a misdemeanour and is liable to imprisonment with hard labour for two years.

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Improperly or indecently interfering with, or offer[ing] any indignity to, any dead human body or human remains [is also prohibited].[2]

While there is no reference to actual cannibalism in the Queensland Code, occasionally endocannibals were prosecuted, principally as body snatchers[3]. These sporadic cases, many of which were heard in the early 1900s, were not part of any orchestrated campaign of repression to quash endocannibalism. Moreover, it is interesting to note that laws which had been on the books for more than one half a century were entirely ineffectual in curbing practices conducive to transmission of kuru, which attained a peak incidence in the 1960s. Rather the occasional indictments for 'improper and indecent interference with a dead human body' probably served only to stigmatize traditional funereal practices and impelled native denial of their existence.

Medical misdirections

The fact that ritualistic cannibalism became covert was to have serious epidemiological implications and greatly frustrated an understanding of both the mode of transmission and the nature of the etiologic agent responsible for the spread of kuru. By the late 1950s, members of the Fore linguistic group, which was particularly devastated by kuru, were dying at an appalling rate: 'a total of 3000 patients [in a population under 10 000] died of kuru in th[e] sixteen year period of kuru surveillance [from 1957 through 1973]'[4]. Countless members of the Fore community perished before accurate information about traditional burial practices was finally elicited after prolonged study by anthropologists who were willing to suspend judgement and thereby ultimately obtain the confidence of their informants.

The failure of earlier medical investigators to obtain accurate information about the continued existence of endocannibalism meant that the practice was overlooked as a possible mode of transmission. Since plausible alternatives about the person to person spread of disease were not forthcoming, for a time the paradigm of communicable disease seemed inapplicable to kuru. Missing data about cultural practices, and the peculiar age and sex incidence of disease - young children appeared to be at equal risk of contracting the disease, while adult women were more than 14 times more likely to suffer from kuru than men within the same tribal and family units[5] - lead to certain erroneous hypotheses about a recessive sex linked genetic cause of kuru: afflicted boys and girls who were 'homozygous' for the 'kuru trait' died in childhood. Heterozygous women, under this hypothesis, were at lower risk of dying young from kuru, but adversely affected later in life.

This mistaken belief that kuru might be due to hereditary causes was perpetuated by other artefacts. Kuru never occurred in immigrants of European descent who had lived in 'kuru areas' since the 1950s. Moreover, the aggregation of cases within families, particularly among a mother and her children indicated to some that either genetic determination of kuru or perinatal transmission of a 'kurugenic agent' was possible.

Preliminary evidence to refute a genetic explanation for kuru first emerged based on ethnographies. In studying the patterns of marriage and family formation, anthropologists had observed that individuals from tribes that experienced little or no kuru, did contract the disease when they intermarried with members of the Fore tribe. By the same token, Fore women who married out of the tribe often went on to contract kuru; however, the offspring did not succumb to the disease. This latter observation of subsequent generations appeared to invalidate at the very least the notion that 'heterozygous' individuals could suffer from kuru.

Anthropological evidence also pointed to a second incongruity in the genetic hypothesis. The Fore notion of the family was not based solely on biological grounds, but could be 'created' or 'generated' by formal proceedings between strangers with no known cosanguineal ties[6]. Elevated incidence rates of kuru were quite common among these 'fictional kinsmen' who were not genetically related. In sum, on the basis of the eventual ethnographic data, it could be 'provisionally concluded . . . that familial environmental factors [were] likely to have been more important than genetic factors in determining familial aggregation and individual liability to kuru'[7].

Even after endocannibalism had been implicated in the transmission of kuru, the practice did not disappear altogether; there were occasional reports from 'outlying villages or isolated hamlets'[4]. It would doubtless strike some as ironic, that after many kuru cases had been ascribed to cannibalism, the government became markedly less willing to prosecute this practice. Indeed when the case of Noboi-Bosai and others came to trial 1971, a very interesting precedent was established. Although 'the facts showed quite clearly that each of the accused had eaten part of one Sumagi's dead body,'[3] all were acquitted of any wrongdoing.

The judge in the case applied a culturally relativistic standard in holding for the defense:

Concepts of decency and propriety (and obscenity) appear in many places of the ordinances and laws of Papua and New Guinea. Having regard to the multifarious customs, languages, dress, beliefs, degrees of civilisation, and social organisation among the people who live in remote wilderness, some where Europeans have yet walked only a few occasions, one cannot conceive that the legislature would have intended to impose uniform blanket standards of decency and propriety, on all the peoples of the country. In assessing propriety and decency of behaviour in relation to corpses in the Gabusi area, I should endeavour to apply the standards so far as I can ascertain them, of the reasonable primitive Gabusi villager . . . in early 1971 . . . The funerary customs of the peoples of Papua New Guinea have been, and in many cases remain, bizarre in the extreme. These are matters of notoriety. Can it be said that the Government of Papua in 1902 by adoption of the Queensland Criminal Code, and in particular [this section], was intending to make so many varied pious, ritual, strength-seeking practices, indecent and improper? I cannot find so[8]

This and similar findings clearly negate assertions of 'rigorous control by the state, of a single form of deviant social behaviour'[1].

A question arises from the standpoint of public health as to whether - given the extraordinary virulence of kuru and the seemingly unmistakable role of endocannibalism in its transmission - the jurist, in this example, behaved irresponsibly and set a dangerous precedent by applying special standards and showing leniency; might it have been in the best interest of the community to have made an example of Noboi-Bosai and the other defendants and to have

convicted them of engaging in 'aberrant social behaviour'; should endocannibalism have been decried and all its practitioners punished if the intent was truly to curb an unhealthful culture-bound practice with the unfortunate potential it poses for the spread of a lethal disease?

The answer to all these questions is 'no': as explained above, previous convictions in cases of endocannibalism did nothing to curb the practice, but simply forced it to become more clandestine. The eventual decline in customs responsible for kuru and corresponding decrease in the incidence of disease was gradual, occurring during a 'period of acculturation from a stone age culture, practicing endocannibalistic consumption of dead kinsmen as a rite of mourning, to a modern coffee-planting society practicing cash economy'[4]. If one wishes, then, to draw an analogy to AIDS, it is only logical to infer that a campaign of repression has no role in curbing the present epidemic. One shudders to think what the implications for AIDS might have been if homosexuality were presently illegal and the first individuals who presented with Pneumocystis carinii and mucosal candidiasis had not revealed their sexual orientation. Years might have elapsed before certain high risk sexual practices, that were particularly popular among homosexual and bisexual men at the outset of this epidemic, were elucidated and the actual number of those infected might be infinitely greater than it already is.

Instead, an alert clinician perceived that 'Pneumocystis carinii pneumonia and mucosal candidiasis in previously healthy men, [who were willing to admit to being homosexual]' was 'evidence of a new acquired cellular immunodeficiency'[9]. These findings, in addition to reports of Kaposi's sarcoma in patients who also acknowledged a history of homosexuality, were vital for the preliminary assembly of a clinical portrait of AIDS, which has of course been greatly elaborated in subsequent years. It is indeed sobering to think that none of this information might be available to this date if members of 'minority groups . . . which historically most societies have abhorred'[1] had felt too shunned and too compromised to admit their 'preference for traumatic interference with each other's lower intestinal tracts'[1].

Learning from the Fore

Historically, punitive legal remedies have been a mostly ineffectual, if not counterproductive, means by which to curb the spread of infectious diseases. If, as has been argued, efforts to eradicate kuru did not involve rigorous state control of deviant behaviour in a particular Melanesian society, what of relevance to the current AIDS epidemic, what can indeed be learned from the study of kuru? Perhaps the most interesting response to the disease was that of the Fore tribespeople whom it afflicted. While the Fore accurately described the symptomatology of kuru, and used this information in their classification of the disease and the name they assigned to it, Fore explanations of the aetiology departed radically from those found in Western medical sources. The Fore discounted any notion that kuru was an infectious disease. Instead, they attributed its existence to an elaborate system of malevolent sorcery. Highland peoples went to great lengths to elude kuru sorcerers and practised what, by their standards, can only be described as preventive medicine against the dreaded disease.

> Men and women attempt to deprive the sorcerer of the materials he needs, and much day behaviour involves the hiding of hair or nail clippings and of food scraps. When women move from an old to a new house they take care not to overlook fragments of old clothing. They scrupulously hide menstrual blood, the emissions from childbirth and an infant's umbilical cord, in response to what they observe to be a high incidence of post-partum kuru'[10].

To dismiss such activities as pointless and superstitious is to overlook a crucial underlying premise: that in denying that kuru might be a contagious disease, the Fore probably preserved a degree of cohesion of their society and ensured that victims of the disease would receive care. The photographs of Fore people assisting their kuru stricken kin is in telling contrast to the panicked response to AIDS in industrial societies, where a tendency to ostracize sufferers has often predominated.

While it would be unfair to minimize the dissension caused in Fore society by the vengeful searches for sorcerers, this retaliatory 'outlet' was modified by kibungs, mass meetings intended to defuse mutual aggression[11]. Moreover, it seems reasonable to assume that it is far less destructive for a society to believe that a ruinous disease is the work of sorcerers residing in hostile parishes, rather than the fault of 'deviants' within its midst. The unwavering refusal of the Fore, for the entire duration of the kuru epidemic, to blame the victims of disease is certainly a valuable example with great relevance to our own comportment in the current AIDS epidemic.

During the past 7 years there have been many tragedies, most involving the inexorable progression of disease and a mounting toll of untimely deaths which our ignorance is powerless to check. Certain tragedies, however, could have been prevented. The stricken, in these instances, have been ostensibly healthy individuals perceived as threatening repositories of AIDS; some were in fact infected, while others were thought to be because they fit popular stereotypes of those at high risk, like male homosexuals. While none of these AIDS 'victims' succumbed to disease, they were nonetheless condemned by societal prejudice. Perhaps the most poignant case to date in the US has been that of three young haemophiliac brothers. Their seropositivity became public knowledge and resulted in truly aberrant social behaviour: the persecution of three small children. 'The boys were expelled from school, subjected to a . . . [protracted] court battle and shunned by their playmates. Their barber of many years refused to continue cutting their hair, their minister asked them to stop coming to church' and the family's home was destroyed by arson[12].

The 'ultimate virological nightmare'[1] has clearly been paralleled by a sociological nightmare. The latter can be curtailed, but only through commitment to an interdisciplinary approach and recognition on the part of medical scientists of anthropological imperatives.

The approach advocated by Seale is an indefensible response to any infectious disease, particularly one as serious as AIDS. A clinician or epidemiologist working amidst alien social groups should adopt the stance of a medical anthropologist and retain a sense of cultural relativism whenever possible. It is not incidental that D Carelton Gajdusek, who made the greatest scientific contribution to understanding the aetiology of kuru, examined social aspects of kuru as

thoroughly as biological ones. Gajdusek never condemned the Fore for what many would doubtless consider barbarian ways and ultimately came to believe that among the Fore 'ritual cannibalism, which was practiced by close relatives of the deceased as a rite of respect, was not very different from crying at western funerals'[13]. While one might not fully accept this assessment, it is hard to deny that it is in such a spirit of open mindedness - and not censoriousness - that the study of AIDS, kuru and unfamiliar social behaviour should be undertaken.

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